

Where can I go for more information about Fragile X syndrome?

The National Institute of Child Health and Human Development (NICHD)

The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from the reproductive process, and that all children have the chance to fulfill their potential for a healthy and productive life, free of disease or disability. The NICHD Information Resource Center is your one-stop source for NICHD brochures, booklets, and other materials related to the health of children, adults, families, and populations.

You can contact the NICHD Information Resource Center at:

Mail: P.O. Box 3006, Rockville, MD 20847
Phone: 1-800-370-2943
Fax: 301-984-1473
E-mail: NICHDInformationResourceCenter@mail.nih.gov
Internet: www.nichd.nih.gov

National organizations

The following organizations of families affected by Fragile X are excellent sources of practical information and support. Each of these organizations publishes a newsletter with up-to-date information about current research, conferences, and legislation.

FRAXA Research Foundation



Run by parents, relatives, and friends of those with Fragile X, as well as by medical professionals. Promotes and funds scientific research aimed at the treatment and cure of Fragile X. Publishes a newsletter and other materials, including a CD-ROM, about Fragile X; maintains a Web site and a listserv about Fragile X; and organizes advocacy and fundraising events around the country.

Mail: 45 Pleasant Street
Newburyport, MA 01950
Phone: 978-462-1866
Fax: 978-463-9985
E-mail: info@fraxa.org
Internet: www.fraxa.org

National Fragile X Foundation



Provides information and support to individuals with Fragile X, their families, educators, and health professionals. Sponsors conferences and publishes a quarterly newsletter. Offers a list of print and other media materials about Fragile X for children, families, and health care professionals. Offers telephone consultation and referrals to medical and genetic services. Contains detailed information on its Web site about the causes and treatment of Fragile X and about Fragile X research. Also provides information in Spanish.

Mail: P.O. Box 190488
San Francisco, CA 94119-0488
Phone: 800-688-8765
Fax: 925-938-9315
E-mail: NATLFX@FragileX.org
Internet: www.fragilex.org

Conquer Fragile X Foundation



Seeks to create strong, dynamic linkages between Fragile X researchers in the United States and those abroad. Supports Fragile X research projects and encourages creative approaches to strengthen the body of Fragile X research through cooperation and coordination of research efforts.

Mail: 450 Royal Palm Way
Suite 400
Palm Beach, FL 33480
Phone: 561-842-9219
Fax: 877-275-1192
E-mail: mail@cfxf.org
Internet: www.cfxf.org

Additional Resources

- **The ARC of the United States**—1010 Wayne Avenue, Suite 650, Silver Spring, MD 20910; 301-565-3842; fax 301-565-3843; www.thearc.org.
- **American Association on Mental Retardation**—444 North Capitol Street, NW, Suite 846, Washington, DC 20001-1512; 202-387-1968 or 800-424-3688; fax 202-387-2193; www.aamr.org.
- **Association of University Centers on Disabilities**—8630 Fenton Street, Suite 410, Silver Spring, MD 20910; 301-588-8252; fax 301-588-2842; www.aucd.org.
- The **Dolan DNA Learning Center, Cold Spring Harbor Laboratory** provides clear explanations of the cause, diagnosis, and treatment of Fragile X; www.dnalc.org.
- **GeneTests Web site.** Funded in part by the National Library of Medicine at the NIH, the Web site provides information on genetic disorders, testing, and contact information for clinical laboratories that do genetic tests; www.genetests.org.
- **American Academy of Pediatrics.** (1996). Policy Statement: Health Supervision for Children with Fragile X Syndrome. *Pediatrics* 98(2):297-300. Available online at www.aap.org/policy/01493.html.

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- ⁴ From the *Your Genes, Your Health* Web site, Dolan DNA Learning Center, Cold Spring Harbor Laboratory; www.yourgenesyourhealth.org/ygyh/mason/ygyh.html?syndrome=fragx.
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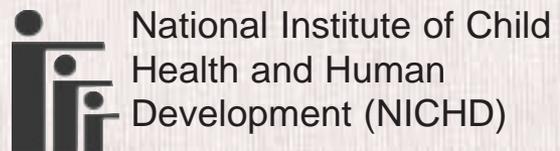
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